

The Effect on Disease Management of Planned Education in Epilepsy Patients: Systematic Review

ABSTRACT

Epilepsy is a disease mostly seen in the central nervous system. The number of people affected is quite high in the World and in Turkey. Individuals with epilepsy and their families need to be trained to control the disease and reduce their anxiety. In effective management of the disease; self-efficacy, quality of life, and having knowledge about disease are important. Informing patients and parents about epilepsy by nurses plays an important role in increasing the success of disease management. The aim of this systematic review study is to determine the effect of planned education for adults with epilepsy on disease management and to provide evidence that healthcare professionals can benefit from.

Keywords: *Epilepsy, disease management, systematic review*

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Introduction

Epilepsy is a clinical picture that repeats with or without convulsion in nervous system, is characterized by loss of consciousness, and occurs as a result of abnormal neuronal discharge which is commonly observed in the central nervous system.¹

It is one of the most common neurological diseases affecting more than 50 million people throughout the world.² Epilepsy prevalence was found to be 19.8³ per thousand in a study conducted with the elderly people aged 65 years and over in the USA and 6.6 per thousand in a study conducted in rural areas in Bolivia.⁴ It has been determined that about 10 people out of every 1000 people and totally 800.000 people suffer from epilepsy disease.⁵ Also, in a retrospective study investigating the epilepsy patients who applied to a hospital in Turkey, the epilepsy prevalence was found to be 17.2 per thousand.⁶

If patients are not informed about the diagnosis and treatment of epilepsy and points to consider and they are socially stigmatized as from the first day when they are diagnosed with epilepsy, then this affects the disease management and coping negatively. These negative conditions cause restrictions in the physical, emotional, intellectual, and social lives of the individuals, lead to traumatic changes in many areas of life and impair their quality of life. Eliminating these problems has vital importance for patients.⁷ For this reason, the patients and their families should be supported and trained in terms of the management of epilepsy.⁸

Epileptic seizures are divided into two (partial and generalized) and they affect the daily activities, driving, work life, school life, and sexual life of individuals. In this sense, providing a good disease management will contribute to the individuals in coping with the abovementioned problems appropriately. Self-efficacy belief and quality of life are the main behavior contributing to the disease management in epilepsy. Nurses should plan nursing activities to enhance quality of life and self-efficacy of these patients. Also, patients should be evaluated holistically and in a multi-dimensional way, their care needs should be determined and they should be equipped with the required knowledge and skills to meet their own care needs.^{9,10} Self-efficacy belief, which is among the effective criteria in the disease management, is important in understanding the decision making process of the patients in the management of epilepsy. Self-efficacy related to the seizure is the belief of the individuals that they can perform enough to cope with the seizures efficiently. It has been stated that the individuals which have high educational level and are affected by epilepsy at young age have more knowledge about the disease and this means self-efficacy.¹¹ In a study demonstrating that self-efficacy was related to management behaviors, it was demonstrated that the individuals with high self-efficacy were more successful in

This study was presented as an oral presentation at the congress (3rd International Health Sciences and Management Conference) held in Sofia, Bulgaria on 3-5 October 2018.

Akdeniz E, Özer Z, Öncel S. The Effect on Disease Management of Planned Education in Epilepsy Patients: Systematic Review. *J Educ Res Nurs*. 2021;18(2):188-195.

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Received: June 26, 2019
Accepted: November 1, 2019



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Table 1. The Screening Strategy Based on PICOS

Database	Disease	Disease Management	Disease Education	Study Type
International	Epilepsy, epileptic, epilepsies, epileptic syndrome, epileptic equivalent, epileptic dementia, epileptic psychosis, awaken, awakesness, awakening, seizure, epileptic seizure, epileptic seizures, epilepsy seizure, seizures epilepsy, seizure disorder, seizure control, epileptoid tremor, seizure induced, brain damage, cryptogenic, cryptogenic epilepsy, cryptogenic partial epilepsy, aura, epileptic aura, aura epilepsy	Disease management, epilepsy management, self-management	Education, effect of education, epilepsy education, training programs, educational activities, education program	Randomized controlled trial
National	Epilepsy	Disease management, self-management	Education, epilepsy education, education program	Randomized controlled trial

managing their own health. The individuals with high self-efficacy belief have higher compliance to treatment their quality of life enhances, and frequency of seizures decreases.¹²

Quality of life is another subject in the management of epilepsy. Seizure concern, having frequent seizure, sleep disorders, depression, regular medication use and economic status affect the quality of lives of the epilepsy patients.¹³⁻¹⁵ The health of the individuals having seizures worsens. As a result, the epilepsy patients face with being rejected for a job or job loss so they have to limit some of their social activities requiring financial power. Such patients should be followed and supported socially.⁹ Early diagnosis and treatment of the psychiatric problems such as sleep disorders and depression, eliminating the factors causing medicine incompatibilities, and when required, getting help from psychiatry department have an important role in enhancing the quality of life.¹⁵⁻¹⁷

Planned training for the individuals (in which the training materials such as slide, brochure, video, animation, epilepsy training booklet, case studies, training program are used, pre-test are applied before the training, follow-up is performed one, one and a half month, two, three, and six months after pretest) and having the patients acquire the correct knowledge on epilepsy are important in terms of increasing the power of coping with the problems of the patients and their families, improving self-efficacy, keeping and improving skills, meeting the need of information, increasing the independency, and enhancing quality of life. For this reason, nurses should evaluate the patients multi-dimensionally and holistically, determine their needs and accordingly provide training.^{9,18} In order to help the individuals diagnosed with epilepsy and control the disease, it is important that the patients are informed and interventions are performed for reducing their concerns. In the literature, it has been determined that the increasing knowledge level affects the attitude towards the disease positively and the younger individuals have more knowledge and positive attitudes.¹⁹ In a study conducted on the compliance to medicine in the epilepsy management, it was stated that the patients and their families were required to be supported and trained continuously to have the epilepsy patients to develop behaviors such as taking medicine regularly and knowing the side effects of medicine.²⁰

This systematic review will be guiding in decreasing the seizure frequency of the epilepsy patients, providing medication adherence, increasing self-efficacy belief and quality of life and about the criteria which health professionals will assess. Also, health professionals will be able to plan the care of the epilepsy patients and/or their families.

The aim of this systematic review is to determine the effect of the planned training provided for the adults with epilepsy on the disease management

and to provide evidence which health professionals can benefit from. In this review, the answer of the question “What are the planned training interventions provided for the epilepsy patients in health management and their effects in decreasing the seizures?” was sought.

Methods

Screening was performed retrospectively from December 2017. Only randomized controlled studies were included in the study due to their high evidence level. The screening lasted for a total of three months to perform the diagnosis, separating, selecting, and inclusion criteria. The screening was performed in ‘Turk Medline, Ulakbim, Ovid, Springer Link, ProQuest, Network Digital Library, Yök Tez, Science Direct, PubMed, CINAHL, Cochrane and Web of Science’ databases. In the study, the keywords were determined by MeSH terms and the screening was performed using Boolean (or/and) operators and the combinations of the keywords in the table below in the national and international databases (Table 1).

The studies, the full text of which was accessed, which had appropriate keywords in their titles and abstracts, and the language of which was English or Turkish, were included in the screening. The selected studies were examined based on PICOS (Population Intervention Comparison Outcome Study Design) and the inclusion and exclusion criteria were prepared based on PICOS. ‘P’ refers to patient population, ‘I’ refers to intervention and exposure, ‘C’ refers to the compared group, ‘O’ refers to the result, and ‘S’ refers to the type of the study⁽²¹⁾.

In this systematic review;

Inclusion criteria:

Population: All the patients with epilepsy and at and over the age of 15,

Intervention: The studies in which planned patient training has been performed in the disease management in patients with epilepsy,

Comparison: Routine care,

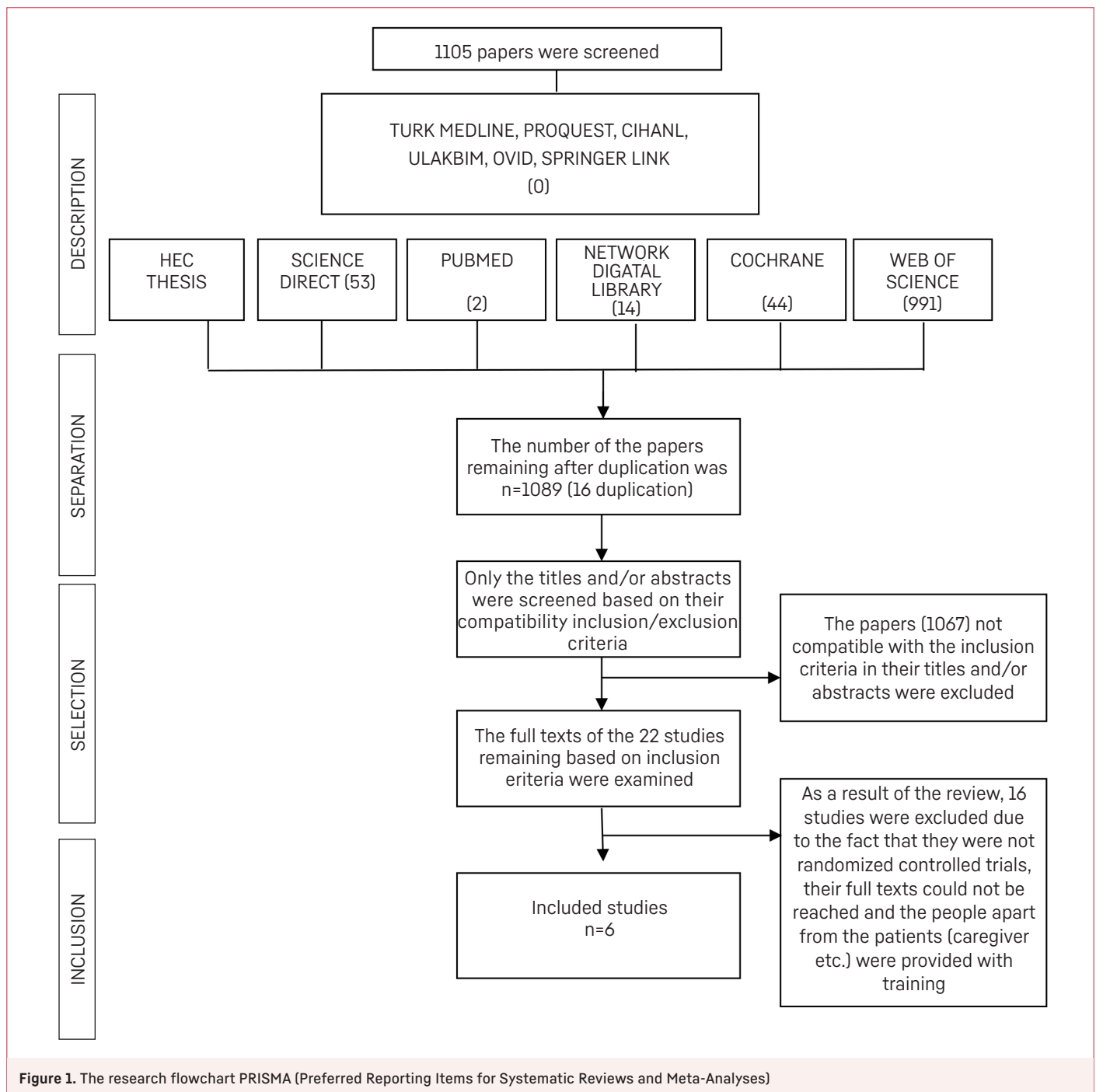
Conclusion: The ones with at least one measurable result about the epilepsy management (self-efficacy, quality of life, self-management),

Study type: Randomized controlled studies.

Language of the study: The studies in English/Turkish

Exclusion criteria:

Population: The individuals without the epilepsy diagnosis and the children diagnosed with epilepsy under the age of 15



Intervention: The studies not assessing the effect of the planned training in the disease management (the studies in which several training materials were not used and periodic follow-ups were not performed),

Comparison: Those not compared with regular care,

Conclusion: The studies with immeasurable results on the epilepsy management,

Study type: All the studies apart from the randomized controlled studies.

Results

Result of screening

The sample of the study included 405 people in the interventional group and 421 people in the control group. As a result of the literature review, a total of 1105 studies (in HEC Thesis: 1, Science Direct: 53, PubMed: 2, Cochrane: 44, Web of Science: 991 Network Digital Library: 14 and the other databases: 0) were found. The repetitive 16 papers were excluded and the remaining 1089 papers were examined based on the inclusion criteria. After all the examination was completed, six

Table 2. Data Extraction

Author, Year, Country	Participants	Intervention	Follow-up	Measuring Tools	Results
Yadegary et al. ²⁴ 2015 Iran	The patients with epilepsy aged between 18 and 65 years Intervention group:30 Control group:30	Intervention: Training and routine care. The training was composed of 2 parts. Three sessions were held: In the first part, the definition of epilepsy and seizure, seizure types, epilepsy diagnosis, observation and classification of its reasons; in the 2nd part drug management, information management, security management, life style and seizure management for encouraging self-management. Control: Routine care	Before the intervention 1 month	Quality of life Quality of life in Epilepsy Survey (QOLIE-31-P)	When the self-management training program was compared with the control group, the quality of life mean score of the patients with epilepsy in the intervention group increased.
Fraser et al. ²⁷ 2015 The United States of America	The patients with epilepsy Older than 18 years Intervention group: 46 Control Group: 46	Intervention: The content of training was composed of the epilepsy and medical subjects, coping with stress, managing epilepsy disease, my health, my vitality, self-confident communication. Control: Routine care	Start 2 months 6 months	Quality of life Quality of life in Epilepsy-31 Survey (QOLIE-31) Self-management Epilepsy Self-management Scale (ESMS) Self-efficacy Epilepsy Self-Efficacy Scale (ESES)	After the first two months, with the training provided, the self-management and the sub-dimensions of self-management (knowledge, drug, seizure and lifestyle management, self-efficacy, quality of life and its sub-dimensions (affective goodness, general quality of life, energy/fatigue); After six months following the training, the increase in the situations such as self-management and its sub-dimension information management, and the sub-dimensions of the quality of life the drug interaction, energy/fatigue, were significantly higher in the mean scores of the intervention groups compared to the increase of the mean scores of the control groups. For the other results assessed, there was no difference between the two groups
Dash et al. ²⁶ 2015 India	Patients with epilepsy at and over the age of 15 years Intervention group:90 Control group:90	Intervention: The content of training was composed of the definition, diagnosis and treatment of epilepsy, and the life and employment problems with epilepsy. Control: Routine care	Start 6 months	Self management Modified Morisky Medication Adherence Scale (MMAS) Self-efficacy Epilepsy Self-Efficacy Scale (ESES)	Compared to the control group, the medication adherence increased in the intervention group after the training. For the other results assessed, there was no difference between the two groups (Self-efficacy)

Table 2. Data Extraction (Continue)					
Author, Year, Country	Participants	Intervention	Follow-up	Measuring Tools	Results
Aliasgharpour et al. ²³ 2013 Iran	Patients with epilepsy between 18-70 years of age Intervention group:30 Control group:30	Intervention: In the training content, the first part included the definition of epilepsy, the definition of brain seizure activities, different seizure type definitions, seizure observations and classification, causes and diagnosis methods; the second part included the self-management information consisting of three parts: including medication, information, seizure, safety and life style training. Control: Routine care	Start After 1 month	Socio-demographic Survey Self management Epilepsy Self-management Scale (ESMS)	Compared to the control group, the self-management scale mean score increased after the training provided for the intervention group.
Dilorio et al. ¹⁰ 2011 The United States of America	Patients with epilepsy at and over the age of 15 years Intervention group:96 Control group:96	Intervention: WebEase (Epilepsy consciousness support and training) is the online epilepsy self-management program for helping medication adherence, stress management, improving sleep quality. In the training, the medication and stress sleep management was completed and then the other stage started in the module. Control: Routine care	Start 1,5 months 3 months	Self management Medication Adherence Scale (MAS) Epilepsy Self-management Scale (ESMS) Pittsburg Sleep Quality Index (PSQI) Psychological state Perceived Stress Scale (PSS) Self-efficacy Epilepsy Self-Efficacy Scale (ESES)	After the WebEase training program, the sleep quality, self-efficacy, medication adherence, self-management scale mean scores increased and the stress level decreased in the intervention group.
May and Pfafflin ²² 2002 Germany	patients with epilepsy aged between 16 and 80 years Intervention group:113 Control group:129	Intervention: MOSES (Modular services package epilepsy). Those in the intervention group were informed about epilepsy, seizure, seizure frequency, stigma, medication adherence, and coping by using MOSES. Control: Routine care	Before the intervention After 6 months	Psychological state Von Zerssen Depression Scale Sf-36 rosenberg Self-esteem Scale, Self management The scales for epilepsy (Limitations in daily life, fears about epilepsy, coping adherence with epilepsy)	Compared to the control group, there were an increase in information about epilepsy and self-respect and a decrease in the fears related to the seizure frequency in the intervention group. For the other results assessed, there was no difference between the two groups

papers were included in the study (Figure 1). The selection period of the papers was performed by all the researchers in different dates independently and assessed in terms of the inclusion criteria.

Data extraction

During data processing, author, year, country, the characteristics of the participants, the intervention performed (the content and type of the training provided), follow-up frequency, the data collection tools used and the results were assessed (Table 2).

The characteristics of the included studies

Two of the research studies included in this systematic review were conducted in Iran, two of them were conducted in the United States

of America (USA) and the others were conducted in India and Germany. All the studies included in the review were randomized controlled studies (Table 1). Within these studies, the highest sample size was observed in a study conducted in Germany in 2002 (242 participants; 113 intervention, 129 control)²² and the lowest sample size was observed in two separate studies conducted in Iran (a total of 60 patients: 30 intervention and 30 control).^{23,24}

The data collection tools used in the included studies about self-management in epilepsy

All the researchers used the questionnaires describing the socio-demographic characteristics. The Epilepsy Self-Efficacy Scale²⁵⁻²⁷ (ESES) was used in three of the studies conducted to measure the disease

management of the epilepsy patients; Quality of Life in Epilepsy^{22,24,27} / (QOLIE)-31/41/48 was used in two of those studies; Epilepsy Self-Management Scale (ESMS)^{23,25,27} was used in three of them.

The frequency of the planned training interventions and follow-up used in the included studies

Slide and brochure^{23,26,27} were used as training materials in three of the studies included in the review, video and animation²⁶ in one of them, epilepsy training booklet²⁴ was used in one of them, case studies²³ were used in one of them and training program was used in three of them.^{22,25,27} When the follow-up frequency of the studies was examined, it was determined that pretest was applied in all the studies included in the review before training and post test was applied one month^{23,24}, one and a half month²⁵, two months²⁷, three months²⁵ and six months^{22,26,27} after pretest.

Measurement criteria discussed in epilepsy management

The studies assessing self-efficacy

In the study by Dilorio et al.²⁵ assessing self-efficacy, they found that self-efficacy mean score was 38.30 in the pretest and 40.21 in the posttest in the intervention group and the mean score was 32.94 in the pretest and 32.88 in the posttest in the control group ($P = .013$).

Also, in their study Fraser et al.²⁷ stated that at the end of eight weeks, the self-efficacy mean score was 8.1 in the intervention group and 7.7 in the control group ($P < .001$).

Dash et al.²⁶ did not find a significant difference between the self-efficacy mean scores of the intervention and control groups.

The studies on the quality of life

In the study of Fraser et al.²⁷ in which the quality of life was assessed, they found that the quality of life mean score of the epilepsy patients after eight weeks was 63 in the intervention group and 58 in the control group and the difference between them was significant ($P = .002$). In the same study, there was no difference between the quality of life total mean scores of the intervention and control groups after six months and it was determined that the difference between the intervention and control groups in the effects of drugs (intervention: 65, control: 59) and energy/fatigue (intervention:53, control:51) subscales was significant.

In the study by Yadegary et al.²⁴, the difference in the control group between the quality of life total score and its subscale scores before the intervention was insignificant. In the intervention group, the mean scores of the quality of life (53.41 before the intervention, 73.66 after the intervention), social functionality (54.77 before the intervention, 75.66 after the intervention), the effect of drugs (44.62 before the intervention, 75.37 after the intervention), cognitive functionality (50.38 before the intervention, 75.37 after the intervention), energy/fatigue (47.66 before the intervention, 73.83 after the intervention), mental health (48.13 before the intervention, 72.53 after the intervention), concern about seizures (22.60 before the intervention, 67.93 after the intervention) and the total quality of life mean scores (48.67 before the intervention, 72.18 after the intervention) increased.

The studies assessing self-management

When the self-management applications were examined in the studies included in the study; in the study by May and Pfafflin²², the rate of the patients who did not have seizure in the last six months or have had seizures once or twice in the last six months increased to 50.4% from 35.4% in the intervention group and to 45.8% from 38.7% in the control group. The percentage of the patients with high seizure fre-

quency decreased to 18.6% from 24.7% in the intervention group and to 15.6% from 17.9% in the control group.

In their study, Dash et al.²⁶, reported that decreased seizure frequency was 18.6% in the control group and 34% in the intervention group; the medication adherence mean score was 6.18 in the pretest and 7.53 in the posttest in the intervention group and the difference was observed to be significant ($P = .001$). In the control group, no difference was found between the pretest and posttest in the medication adherence mean scores (pretest mean score=6.46, posttest mean score =6.58).

In the study by Fraser et al.²⁷, the self-management total mean score after the intervention was 3.9 in the intervention group after eight weeks and six months and 3.7 in the control group ($P < .001$).

In their study, Aliasghapour et al.²³, found that 73.3% of the intervention group and 53.3% of the control group stated that their self-management was at medium level at the beginning. At the end of the intervention, 76.7% of the intervention group stated that their self-management was high and 60% of the control group stated that their self-management was at medium level.

In the examination of the assessment criteria of the results of the included studies, the results were found to be significant in the favor of the intervention group in all of the six studies. It was observed that self-efficacy²⁵⁻²⁷ was discussed in three studies, quality of life^{24,27} was discussed in two studies and self-management^{22,23,25-27} was discussed (seizure management, compliance to the disease, medication adherence) in five studies.

Discussion

In this systematic review investigating the effect of planned training on disease management in the epilepsy patients, the results of six studies were examined, the criteria affecting disease management and the effect of training were examined in the included studies.

Self-efficacy is defined as the belief of an individual on how good he/she can perform the actions required to cope with possible issues.²⁸

The self-efficacy in epilepsy is the belief of an individual that he/she can cope with the seizures effectively.²⁹ In a study, it was found that the epilepsy patients with strong self-efficacy were more effective in seizure management.³⁰ It was understood in the literature review that high level of self-efficacy and less depressive symptoms was related to the information about epilepsy³¹, the mobile applications about epilepsy that can be installed on smart phones or tablets increased the knowledge about the disease and self-efficacy for the adolescents with epilepsy³², the individuals with high self-efficacy had higher medication adherence^{33a}, health education in medication adherence is important and more frequent follow-up and population-based studies should be performed for these patients.²⁶ Individual/social training may be held on this subject by health professionals. The use of the applications to be developed by using today's technology (smart phone, tablet, internet etc.) may be useful in improving self-efficacy.

World Health Organization defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".³⁴ In the recent studies conducted on the quality of life of the epilepsy patients, low socio-economic status, depression, sleep disorders and having frequent seizures have affected the quality of life of the epilepsy patients negatively.³⁵⁻³⁹ In a study, it was found that frequent seizures affected the quality of life negatively⁴⁰, and the training of mothers in the training provided for

parents to improved the quality of life and general health status of the pediatric patients.⁴¹ In other studies, it was concluded that depression, sleep disorders and medication adherence were among the factors affecting the quality of life and, therefore, the early diagnosis of depression and sleep disorders were important in improving the quality of life⁴², also seizure severity and epilepsy etiology, anxiety and depression were the main determinants of the quality of life⁴³, early diagnosis and the awareness of the society about epilepsy and the training to be provided by experts will improve the quality of life of the children with epilepsy.⁴⁴ In a study, it was determined that the self-respect and, therefore, the quality of life of the young people living with epilepsy may improve by improving social support and training programs.⁴⁵ In two studies included by their abstracts, it has been revealed that the points such as depression, sleep disorder, number of seizures and medication adherence were important for the quality of life.

In as study conducted in Turkey, it was concluded that the awareness and social support should be raised by increasing the information about epilepsy.⁴⁶ In a systematic review, it was demonstrated that the self-management training provided for the adults with epilepsy (including management of psychological stressors, improvement in seizure management and enhancing the quality of life) improved the information and self-reliance about self-management of the individuals.⁴⁷ In the studies discussed in the review, the seizure frequency decreased with the training intervention, medication adherence and disease management increased and, therefore, an improvement was provided in the self-management applications. The fact that health professionals provide information continuously for the epilepsy patients and their relatives may be useful in increasing the self-efficacy, quality of life and self-management applications.

Conclusion

In three of the studies included, the Epilepsy Self-Efficacy Scale (ESES); the quality of Life in Epilepsy- QOLIE-31/41/48 and Epilepsy Self-Management Scale (ESMS) were used.

In the epilepsy management; it was concluded that the criteria such as having knowledge about the disease, self-efficacy, quality of life and self-management applications were examined (medication adherence, seizure management, sleep disorder, self-respect, stress, concern, seizure frequency). It was observed that the planned training provided for epilepsy patients was effective in decreasing the number of seizures. It was concluded that the planned training intervention provided for the epilepsy patients in the self-efficacy, quality of life and self-management applications (increased sleep quality and self-respect; decrease in stress, concern, seizure frequency and the fears related to epilepsy) was effective in epilepsy management.

Recommendations

It may be recommended that the society is informed by nurses about epilepsy and awareness is raised about epilepsy,

The factors affecting the self-efficacy, quality of life and self-management which are effective in disease management are determined and the measures for the risk groups are taken,

The patients and their families are trained by determining the factors effecting the self-efficacy, quality of life and self-management which are effective in disease management by the health professionals,

As the disease management increases treatment success, more training studies are performed about the disease management,

As the epileptic seizures last for long years, regular follow-ups are performed.

Peer-review: Externally peer-reviewed.

Author Contributions: Concept – E.A., Z.Ö.; Design – E.A., Z.Ö., S.Ö.; Supervision – Z.Ö., S.Ö.; Literature Search – E.A., Z.Ö., S.Ö.; Writing – E.A., Z.Ö., S.Ö.; Critical Reviews – Z.Ö., S.Ö.

Conflict of Interest: The authors have no conflict of interest to declare.

Financial Disclosure: The authors declared that this study has received no financial support.

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